

## **JUNIOR AMBASSADOR ~ LIAM Age 14, Ohio**

Liam is in the 9th grade in Cincinnati, Ohio. When he was 1 month old, he was found to have a sore on his hip. His pediatrician sent him to have some lab work done which revealed a critically low neutrophil count. He was hospitalized for a week at that time, diagnosed with Neutropenia and started on daily Neupogen injections. In the months to follow, genetic testing and a bone marrow biopsy revealed that Liam has Severe Congenital Neutropenia, Elane gene mutation. Liam continues to receive low doses of daily Neupogen injections with great response. He has lab work done at least monthly with an annual bone marrow biopsy for observation. Aside from an occasional skin infection that may require an admission with IV antibiotics, Liam is overall, otherwise a "normal, healthy kid".

When Liam was 8 years old, he was overheard telling his brother's 10-year-old friend all about Neutropenia, lab draws and bone marrow biopsies. It was at that time that his parents realized that Liam needed an opportunity to "tell his story". He started giving presentations to his class every year about his Neutropenia. Since then, Liam and his family have found several ways to help raise awareness about Neutropenia and funds for research and peer support by joining the efforts of the Ella Jewell Foundation and the National Neutropenia Network (NNN). They have held garage sales, Bowling events, Turkey Trots, Painting Nights Out and Power Play events at their local Dave & Buster's. Liam has also been involved in a few of the past NNN summer conferences, sharing his story with parents and physicians as well as being a role model to the younger kids in attendance. Liam continues in these efforts and has even started to expand into his local Cincinnati Children's Hospital community to advocate and give back for all of the blessings he has been given. For all his work on behalf of the Neutropenia community, Liam has earned the title of one of our Junior Ambassadors for 2019-2020....

Liam serves as a member of the Patient Advisory Council and the Champions Program at Cincinnati Children's Hospital. These groups allow Liam to connect with other patients, families and staff at the hospital. The advisory council specifically "gives patients a voice in the decisions that affect how they receive care. They support current patients, help staff see the hospital from patient perspectives, advocate on behalf of patients and identify ways to make Cincinnati Children's a better place for the children they serve." The council has given Liam the ability and accountability to help improve the impact the care has that he and fellow patients receive at the hospital.

The Champions Program offers many different opportunities for becoming involved in the community. Liam has been able to speak multiple times in front of Hospital Leadership teams about his experience as a patient and having Neutropenia-most recently January 2019. December 2018, Liam and his family took part in a telethon for a local tv station to raise money on behalf of Cincinnati Children's Hospital. He was given the opportunity to present a check from an annual fundraiser to the hospital for Neutropenia research being conducted at Cincinnati Children's-the tv host also interviewed Liam live which allowed Liam to raise awareness about Neutropenia, what it's like to have grown up with it and how he is treated for the rare disease. And, this past February, Liam participated in a radiothon, once again to help raise money for the hospital. He was interviewed live on the radio as well and educated listeners about Neutropenia. All of these opportunities have been invaluable to Liam, as they really help him to take ownership of his Neutropenia and take pride in being able to make a difference with the gift he has been given in life.

Every November since 2013, Liam's family holds an event to raise funds and awareness for Neutropenia research and peer support. Last year, Power Play 4 Neutropenia was held at a local Dave & Buster's restaurant where over 220 people attended, enjoyed brunch, game play, basket raffles with winnings donated from local businesses/family/friends. As always at these events, Liam was the MC and had the opportunity to introduce one of his treating physicians who spoke about Neutropenia; he also introduced a Neutropenia dad who spoke about a parent's perspective. Liam utilizes these events to spread Neutropenia awareness as well as to bond with other kids with Neutropenia with whom he has forged a priceless friendship with over the years. To date, Liam and his family have proudly raised over \$61,000 for Neutropenia research and peer support.

